

Special Addition



children with special health care needs

A NEWSLETTER FOR MISSOURI FAMILIES

A publication of the Missouri
Department of Health,
Bureau of Special Health
Care Needs



In this Issue

BSHCN Family Advisory
Council

KAT

Local Compliance to ADA

The Nine Commandments
of Family-Centered Care

Chat with the Chief

Helpful Websites

Family Voices
www.familyvoices.org

HRSA
www.hrsa.dhhs.gov

Federal Viewpoint

Achieving success for all children with special health care needs by 2010: creating a 10-year action plan

by Merle McPherson, MD, Director, and
Gloria Weissman, Deputy Director, Division
of Services for Children with Special Health
Needs, Maternal and Child Health Bureau,
Health Resources and Services Agency

A new century has arrived and, with it, exciting new opportunities to renew our commitment to achieving success for all children with special health care needs.

During the past 20 years, a new model of care for special-needs children has emerged. Much of the credit is due to partnerships among federal and state governments, communities, families, providers, and professional and voluntary organizations. In this country, as well as in many others, this model—comprehensive, community-based, family-centered, culturally competent, and coordinated care—is recognized as the one that serves children and families best.

Over the past two decades, working together, we have developed and fine-tuned this model. We have

shown that it produces much better outcomes for children and families and we have begun to put it in place in many communities. But now it is time to make it a reality. It is time to

please see page 2

Local Viewpoint

Bureau of Special Health Care Needs wants to help

The Bureau of Special Health Care Needs in the Division of Maternal, Child and Family Health is a unit of the Missouri Department of Health. The Bureau helps families of children with diagnosed serious and/or chronic medical conditions get treatment related to the child's condition. Eligibility for enrollment in the Bureau of Special Health Care Needs, Children with Special Health Care Needs Program (CSHCN) includes:

1. **Financial & Medical:** Applicants must meet both financial and

please see page 3

continued from page 1 (fed. viewpoint)

see that all children with special health care needs, all their families, all their communities are part of our success story. *Together we can do it.*

Our shared history

Before we move forward, it might be helpful to remember where we have been. Thirty years ago, the term "children with special health care needs" was not part of our vocabulary. Instead, states had "Crippled Children's" programs, and the children they served were seen for diagnosis and correction of defects.

Low expectations led to low achievement. Children with special health care needs often did not live long enough to become adults. Even smaller numbers were able to finish school, find jobs, and go on to lead happy, fulfilling lives.

Families struggled to find services for their children. Caregivers and

policy makers overlooked the fact that families often knew the most about caring for their children. Many families felt ignored and powerless. Families learned to support each other, but had a hard time finding the support they needed.

The 1982 Surgeon General's Workshop on Children with Handicaps and their Families began to change our national vision of what could be possible. Parents and other family members, health professionals, financing experts, partners in school and social service agencies, and local, state, and federal government came together to develop a national agenda for children with special health care needs. Families and more than 70 professional associations signed on to this agenda.

In 1989, new language for Title V of the Social Security Act directed the states to "provide and...promote family-centered, community-based, coordinated care...for children with special health care needs and...facilitate the development of community-based systems of services for such children and their families." In 1990, the federal government put forward *Healthy People 2000*, which called for all states to put these comprehensive systems in place by the year 2000.

What we've accomplished—together

Since 1990, much progress has been made. For example:

■ **Family Voices**, which began as a small organization of families of

children with special health care needs, now provides support and education to both families and providers in every state. Through its leadership,

families are now active participants in everything we undertake at the federal level.

■ **Medical home**, a concept developed with the American Academy of Pediatrics and the Maternal and Child Health Bureau of the Health Resources and Services Administration (HRSA), is designed to make sure that each child with special health care needs has a regular health care provider in his or her community.

The medical home helps identify all the child's needs early, provides ongoing primary care, and coordinates this care with the specialty care and community services needed. Parents, providers, and policy makers across the nation are being trained and supported in their efforts to create medical homes for all our children.

■ **Communities CAN** is a program that has brought national recognition to communities that have comprehensive, coordinated systems of care for children. The program also builds leadership, and provides models that other communities can use.

There have been many other important accomplishments for children with special health care needs over the past 20 years:

A new, broad definition of children with special health care needs has



Special Addition is a free newsletter published twice a year for families of children with special health care needs. MedWired News, Inc., Cincinnati, Ohio (513-791-8382), provided the newsletter design and layout of the national news.

State News Editor
Penny Goff
Missouri Department of Health
PO Box 370
Jefferson City, MO 65102
(573) 751-6246

State Director (RSHCN)
Richard Brown, FACHE, PhD
Missouri Department of Health
PO Box 370
Jefferson City, MO 65102
(573) 751-6246

This newsletter is partially funded by the Maternal and Child Health Bureau (MCHB).

U.S. Department of Health and Human Services



Health Resources and Services Administration
Maternal and Child Health Bureau

please see page 5

continued from page 1 (help)

medical guidelines. To qualify medically the child must have a covered disease, defect, or condition, which may hinder the achievement of normal physical growth and development. Families or individuals whose income is at or below 185% of the U.S. Department of Health and Human Services Poverty Income Guidelines shall be considered financially eligible.

2. **Age:** Birth to age 21.
3. **Coverage:** Children may receive outpatient tests and evaluations and up to five days of inpatient hospitalization at an approved hospital. BSHCN staff will complete a medical review based on physician reports to determine if the child is eligible for "extended" coverage. "Extended" coverage includes inpatient care, surgery, outpatient tests, evaluations, therapies, approved medicines, equipment and supplies.
4. **Service Coordination:** CSHCN provides help in planning and finding medical and other
(continued on page 6)

Local compliance to ADA

For people who are deaf or hard of hearing, the FCC has recognized the growing prevalence of digital TV and has required that by July 1, 2002, digital television receivers must come equipped from the manufacturer with "compliant DTV closed-captioning decoder circuitry."

Provisions of the new rule will also allow viewers to choose and modify the color, size, and font of the captioning and choose between multiple streams of captioning, such as "easy reader" or alternate language captioning.

BSHCN family advisory council

by Sarah Zerr Munday, Family Advisory Council Facilitator



You are invited to be part of a new family advisory council! The Bureau of Special Health Care Needs is forming a new council for family members of children with special health care needs. Not only will you receive information and support and a chance to network with other families, you will have input into major decisions that are made which will affect your child. We will be meeting with key people from the Bureau as well as the community. If you are interested in being a part of this exciting new council, please call Sarah Zerr Munday at 1-800-451-0669.

Network offers free toy adaptations

The National Rehabilitation Awareness Foundation founded its Toy Adaptation Network for Children with Disabilities to help address the need for toy modification. The network served on a panel of experts for the October 2000 Annual Toy Issue. The network comprises 16 providers from around the country. All sites feature staff who are experts in serving children with disabilities, and modifications to toys are done for free. Modifications generally include adding Velcro® straps for better grasping; seat lift devices for elevation; dowels for better hand control; and enlargement of switches

and controls to enable activation.

Services through the network can be accessed through the toll-free hotline, (888) FIX-A-TOY (349-2869). Callers will be directed to the site nearest their home. All sites have been selected based on familiarity and experience with children who have disabilities.

Kids Assistive Technology (KAT)

Kids Assistive Technology (KAT) is a new program to help families pay for assistive technology devices and services for their children. KAT assists children with disabilities by providing funding for assistive technology when no other funding source exists. The program is operated by Missouri Assistive Technology with funding through Missouri's Bureau of Special Health Care Needs. The program is available to children, age birth to 21.

Children with disabilities eligible for the program are those who have or are at increased risk for a chronic physical or developmental condition and who also require health and related services of a type or amount beyond that required by children generally. Preference for funding will be given to children in families of lower income. Children in families with adjusted gross incomes up to \$60,000 will be eligible for consideration in the program. In calculating income eligibility, families may deduct any medical expenses that were eligible for the medical expense deduction on their federal income taxes, but which did not meet the expense threshold. The maximum funding available through the program is \$7,500 per child. To receive an application or ask questions about **Kids Assistive Technology**, contact Missouri

please see page 4

continued from page 3 (KIDS)

Assistive Technology at 816-373-5193.

The Nine Commandments of Family-Centered Care

Quality pediatric care especially as the "new morbidity" takes up more of a pediatrician's time, must be family-centered. To ensure that the care that is provided is family-centered, the "Nine Commandments of Family-Centered Care" should be followed. Adapted from the nine key elements of family-centered care as defined by the American Academy of Pediatrics' Medical Home Training Program.

1. Thou shalt recognize the family as constant in a child's life.

A child's family is probably the only thing in his or her life that remains relatively constant. Recognizing this fact is the underpinning concept of family-centered health care.

2. Thou shalt collaborate, and help other professionals collaborate, with the family in providing consistent quality health care.

Pediatric health professionals need to collaborate with parents, and often other family members, to ensure that a child's health is well cared for. This collaboration encourages parents' confidence in their ability to care for their children, as well as, improves this ability.

3. Thou shalt honor the diversity of families and family members.

No two families and no two family members are alike. Honoring this diversity will not only help to build rapport with the patient and his or her family, but will help to discover

how differing perceptions of health care affect the patient's well being.

4. Thou shalt recognize the strengths of families and family members.

Each family and family member has their own strengths and abilities that they can succeed at. Recognizing these strengths can help to encourage families to use these strengths for the betterment of the patient's health.

5. Thou shalt communicate comprehensive and balanced information to patients and families.

Patients and their families need complete and unbiased information in order to make knowledgeable decisions concerning health care. Pediatricians are a trusted source of this kind of information.

6. Thou shalt promote family-to-family networking and support.

Sometimes what a family or patient needs is to talk with other families or patients experiencing similar situations. Pediatricians need to recognize these situations and help the family find this kind of support when available. By facilitating this support system, it will enhance the well being of patients and build good patient/parent relationships.

7. Thou shalt integrate patients' developmental needs into the care provided.

Problems with behavioral, developmental and social functioning are increasingly being seen in pediatric practice—the so-called "new morbidity". This increase makes it especially important for pediatric health professionals to take developmental needs into consideration when caring for their patients.

8. Thou shalt implement comprehensive policies and programs.

To make the most of a pediatrician's

expertise and that of other professionals in the community—policies must put into writing regarding how their practice makes referrals to subspecialists and community resources and establishes programs for the care of patients with frequently seen conditions.

9. Thou shalt participate in the design of accessible health care systems.

This is especially important if the services provided are in a managed care environment. How the contracts are negotiated affects the care the patients receive; make sure that the contracts not only meet the financial requirements, but the health care needs of the patients.

Chat with the Chief

by Dr. Richard Brown

We are very pleased to introduce the first edition of our newsletter called Special Addition. This newsletter marks the beginning of a new era in the Bureau of Special Health Care Needs in Missouri. It is designed to keep you informed of issues of interest to you.

The Central and Regional office staff have participated in a series of quarterly planning meetings during the past year designed to create a better system of service for families of children with special health care needs. This effort has resulted in the development of plans to establish a family advisory council, a website for families, and community partnerships. Family involvement with the children's advisory council will assist the bureau to better serve children with special health care needs. The website will provide a link to allow families to engage in dialog with each other and

please see page 6

continued from page 2



“It is time to see that all children with special health care needs, their families, and their communities are part of our success story.”



been developed and is now widely accepted: “Children with special health care needs are those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.”

It is a definition that focuses on the services our children need, not on the conditions they have. We want to make sure that the needs of all of these children are met.

A national survey of children with special health care needs is being supported by the HRSA and carried out by the National Center for Health Statistics (NCHS). By 2002, for the first time, we will know how many children with special health care needs are in each state and in the nation.

The survey will also tell us a great deal about what services these children need and are using, how well their care is being coordinated, how well they are covered by health insurance, and how satisfied their families are with the care their children are getting. The information we receive from this survey and others will help us better understand how well we are doing and what gaps remain. It will also help us advocate for better services and systems for our children.

Measuring success

How will we know when we have created the kind of system of care our children deserve? We believe that these six things must happen before we have been successful:

- All children with special health care needs will receive ongoing

comprehensive care within a medical home;

- All families of children with special health care needs will have adequate private and/or public insurance to pay for the services they need;

- All children will be screened early and continuously for special health care needs;

- Services for children with special health care needs and their families will be organized in ways that families can use them easily;

- Families of children with special health care needs will participate in decision-making at all levels and will be satisfied with the services they receive; and

- All youth with special health care needs will receive the services necessary to make appropriate transitions to all aspects of adult life, including adult health care, work, and independence.

State Title V programs are now required to report their progress toward these six outcomes every year. At the Federal level, through our grants and contracts, we are developing models, materials, expert workshops, and other activities to support state and local efforts.

Achieving success: a 10-year action plan

While we want to measure success, achieving success is much more important to us. Late last year, the Federal government rolled out *Healthy People 2010*. Once again, as in *Healthy People 2000*, states and territories were given the task of putting in place service systems for all children with special health care needs.

In partnerships with the March of Dimes, we at HRSA's Maternal and Child Health Bureau have begun a major effort to develop a 10-year action plan for creating a nationwide

please see page 6

continued from page 4 (chat)

exchange mutually beneficial information. The community partnerships are expected to broaden the network of service coordinators throughout the state to serve the special needs population.

Also, an outreach campaign will be launched later this year. The campaign will increase the awareness of services for children with special health care needs to the general population. Stay tuned for future editions.

Please contact us if you have questions or concerns that we can help you with.

continued from page 3 (help)

health-related services for children and their families. Service coordinators work with physicians, nurses, social workers and others to find a medical home.

5. **Payment:** CSHCN is supported by state and federal funding. Families are not expected to participate in the cost of treatment.

6. **Application:** To apply for services, contact the Bureau of Special Health Care Needs at Missouri Department of Health Bureau of Special Health Care Needs
PO Box 570
Jefferson City, MO 65109
1-800-451-0669

continued from page 5 (federal viewpoint)

action plan for creating a system of services for all children with special health care needs.

Six workgroups were formed to create these plans. Each includes members from State Title V programs, families, professional groups, providers, and communities. Each is focusing on one of the six outcomes above, and each is developing an action plan to achieve that outcome.

This summer and fall, those six action plans are being pulled together into one 10-year Action Plan for Children with Special Health Care Needs. This plan will be the basis for a mono-

graph to go along with Healthy People 2010. It will guide our work at the Maternal and Child Health Bureau around children with special healthcare needs and the work of partners for the next ten years. It will have practical steps for putting into place and **keeping** in place the services and supports children with special health care needs and their families need to succeed.

Creating a 10-year plan is an important step, but moving it from paper to action is much more important, and much more difficult. We need all of you to work with us, to support us, to bring your partners along on this next stage of our journey together. With our eye on the prize-our children's future-we can do it...and we will do it! ☐

Future articles will provide updates on this national initiative. For additional information, please contact Gloria Weissman at 301-443-8999 or by e-mail at gwei_sman@hrsa.gov.

Missouri Department of Health
Bureau of Special Health Care Needs
PO Box 570
Jefferson City, MO 65102

Presort Standard
US Postage
Paid
Jefferson City, MO
Permit No. 20

MISSOURI DEPARTMENT OF
HEALTH

All Children Deserve
H OPE
Call the BSHCN Hope Hotline:
1-800-451-0669

An equal opportunity affirmative action employer. Services are provided on a nondiscriminatory basis. This publication may be provided in alternative formats such as Braille, large print or audiotape by contacting the phone number listed above. TDD users can access the above phone number by calling 1-800-735-2966.

continued from page 4 (chat)

exchange mutually beneficial information. The community partnerships are expected to broaden the network of service coordinators throughout the state to serve the special needs population.

Also, an outreach campaign will be launched later this year. The campaign will increase the awareness of services for children with special health care needs to the general population. Stay tuned for future editions.

Please contact us if you have questions or concerns that we can help you with.

continued from page 3 (help)

health-related services for children and their families. Service coordinators work with physicians, nurses, social workers and others to find a medical home.

5. **Payment:** CSHCN is supported by state and federal funding. Families are not expected to participate in the cost of treatment.

6. **Application:** To apply for services, contact the Bureau of Special Health Care Needs at Missouri Department of Health Bureau of Special Health Care Needs
PO Box 570
Jefferson City, MO 65109
1-800-451-0669

continued from page 5 (federal viewpoint)

action plan for creating a system of services for all children with special health care needs.

Six workgroups were formed to create these plans. Each includes members from State Title V programs, families, professional groups, providers, and communities. Each is focusing on one of the six outcomes above, and each is developing an action plan to achieve that outcome.

This summer and fall, those six action plans are being pulled together into one 10-year Action Plan for Children with Special Health Care Needs. This plan will be the basis for a mono-

graph to go along with Healthy People 2010. It will guide our work at the Maternal and Child Health Bureau around children with special healthcare needs and the work of partners for the next ten years. It will have practical steps for putting into place and **keeping** in place the services and supports children with special health care needs and their families need to succeed.

Creating a 10-year plan is an important step, but moving it from paper to action is much more important, and much more difficult. We need all of you to work with us, to support us, to bring your partners along on this next stage of our journey together. With our eye on the prize—our children's future—we can do it...and we will do it! ☐

Future articles will provide updates on this national initiative. For additional information, please contact Gloria Weissman at 301-443-8999 or by e-mail at gweissman@hhs.gov.

Missouri Department of Health
Bureau of Special Health Care Needs
PO Box 570
Jefferson City, MO 65102

Presort Standard
US Postage
Paid
Jefferson City, MO
Permit No. 20

MISSOURI DEPARTMENT OF
HEALTH

All Children Deserve
HOPE
Call the BSHCN Hope Hotline:
1-800-451-0669

An equal opportunity affirmative action employer.
Services are provided on a nondiscriminatory basis. This publication may be provided in alternative formats such as Braille, large print or audiotape by contacting the phone number listed above. TDD users can access the above phone number by calling 1-800-735-2966.